Age and Ageing 2019; **0:** 1–8
doi: 10.1093/ageing/afz043

Patterns of emergency department attendance among older people in the last three months of life and factors associated with frequent attendance: a mortality follow-back survey

Anna E. Bone[1], Catherine J. Evans[1,2], Lesley A. Henson[1], Wei Gao[1], Irene J. Higginson[1], on behalf of BUILDCARE study

[1]Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, UK
[2]Sussex Community NHS Foundation Trust, Brighton, UK

Address correspondence to: Anna Bone. Email: anna.bone@kcl.ac.uk

Abstract

Background: frequent emergency department (ED) attendance at the end of life disrupts care continuity and contradicts most patients' preference for home-based care.
Objective: to examine factors associated with frequent (≥3) end of life ED attendances among older people to identify opportunities to improve care.
Methods: pooled data from two mortality follow-back surveys in England. Respondents were family members of people aged ≥65 who died four to ten months previously. We used multivariable modified Poisson regression to examine illness, service and sociodemographic factors associated with ≥3 ED attendances, and directed content analysis to explore free-text responses.
Results: 688 respondents (responses from 42.0%); most were sons/daughters (60.5%). Mean age at death was 85 years. 36.5% had a primary diagnosis of cancer and 16.3% respiratory disease. 80/661 (12.1%) attended ED ≥3 times, accounting for 43% of all end of life attendances. From the multivariable model, respiratory disease (reference cancer) and ≥2 comorbidities (reference 0) were associated with frequent ED attendance (adjusted prevalence ratio 2.12, 95% CI 1.21–3.71 and 1.81, 1.07–3.06). Those with ≥7 community nursing contacts (reference 0 contacts) were more likely to frequently attend ED (2.65, 1.49–4.72), whereas those identifying a key health professional were less likely (0.58, 0.37–0.88). Analysis of free-text found inadequate community support, lack of coordinated care and untimely hospital discharge were key issues.
Conclusions: assigning a key health professional to older people at increased risk of frequent end of life ED attendance, e.g. those with respiratory disease and/or multiple comorbidities, may reduce ED attendances by improving care coordination.

Keywords

Emergency medicine, Hospitals, Aged, Palliative care, Continuity of patient care

Key points

- 12% of adults aged ≥65 attended the ED ≥3 times in the last 3 months of life, representing 43% of all such ED attendances.
- Older adults with respiratory disease and/or multiple comorbidities were more likely to attend the ED frequently at end of life.
- Association between community nursing visits and frequent ED attendance may reflect short task-based visits from multiple nurses.
- A model of care involving a key health professional to coordinate care may reduce frequent end of life ED attendances.

Introduction

Most people prefer home-based care and to remain close to their family at the end of life [1]. Yet, emergency department (ED) attendance is common in the months before death [2]. Although often an appropriate response to an exacerbation or crisis, ED attendances disrupt continuity of care and can be burdensome, especially for older people with deteriorating health [3]. Frequent attendances to the ED may suggest that community services are unable to respond to increasing needs in a timely manner [4].

Globally, emergency services remain stretched [4]. Population growth and ageing will further exacerbate this in future decades. Deaths are expected to rise 27% by 2040 in England and Wales, with 90% of deaths anticipated in those aged ≥65 years [5]. Recent trends show a rise in the mean number of acute hospital admissions by people in the last year of life in England, most of which occur via the ED [6]. If these trends continue this would equate to an additional 1.3 million admissions per annum by 2041 [7].

Older people nearing the end of life represent an especially vulnerable group. The prevalence of multiple co-existing illnesses and frailty increases with age [8] and there is an increased risk of social isolation and loneliness [9]. A national review of choice in end of life care in England identified that older people with advanced disease have poorer access to the care services they require.

Understanding the factors associated with frequent ED attendances by older people towards the end of life can help identify areas for improvement in care provision. A recent systematic review found that men, those living in a rural area, of non-white ethnicity and those with non-cancer conditions were more likely to attend the ED during the last year of life; people receiving community palliative care or hospice care were less like to attend [10]. The insights of older people and their family are essential for understanding the complex issue of frequent ED attendance, and yet there is limited patient or carer-reported evidence on this issue [11].

We aimed to (i) describe patterns of ED attendance by older people in the last 3 months of life; (ii) examine factors associated with frequent ED attendances, and (iii) explore the circumstances of such attendances, to develop a conceptual model for policy and practice.

Methods

Study design

Pooled data from two mortality follow-back postal surveys: the International Access Rights and Empowerment (IARE) study (2012) [12] and OPTCare Elderly study (2014) [13]. Both surveys were adapted from the QUALYCARE survey [14] to ensure relevance to older people including those with non-cancer conditions. Both studies surveyed the next of kin of people who had died four to ten months previously. The surveys used a combination of closed and open questions about the decedents' last three months of life, including validated measures of health service use (client service receipt inventory) [15] and quality of life (EQ5D) [16].

The design of this study involved quantitative analysis of the pooled survey data to identify factors associated with frequent ED attendance, with exploration of these findings in the free-text comments. Analysis and development of our conceptual model was underpinned by theoretical understanding from Gomes and Higginson's model of place of care at the end of life [17] and Andersen's behavioural model of health service utilisation [18].

Ethical approvals were granted (IARE study: 12/L0/0044; OPTCare Elderly: 12/LO/1367). We followed STROBE reporting guidelines.

Participants and setting

The pooled sample included decedents aged ≥65 with advanced disease (such as cancer, dementia, heart failure; excluding accidental/sudden deaths) and receiving varying levels of palliative care prior to death in South England. In the IARE study, decedents were identified from hospital records and survey invitations sent to next of kin by clinicians. In OPTCare Elderly, decedents were identified from death registration records, and invitations sent by officials. The studies were set in rural and urban areas of South England (Appendix 1, available in *Age and Ageing* online.).

For analysis of free-text responses, we purposively sampled decedents who visited the ED frequently during the last three months of life.

Data sources and variables

Data were reported by the family member of the decedent, apart from age, gender, primary diagnosis and comorbidities, which we obtained from official death registration or hospital records. Our primary outcome was frequent ED attendance in the last three months of life, defined as ≥3 attendances [19]. We selected explanatory variables based on findings from a systematic review and existing models of end of life health service use [10, 17, 20]. These were: (i) sociodemographic (age, gender, marital status, living alone, financial situation and education); (ii) illness (primary diagnosis, comorbidities (count of Charlson conditions [21] additional to primary diagnosis), pain and depression in last three months (EQ5D)); and (iii) service factors (general practitioner visits, community nursing, community palliative care, presence of a key worker involvement, discussion regarding preference for end of life care, spending time in a care home, number of informal carers and informal care hours).

Open questions invited further comments on the care received, for example '*Please feel free to comment on any aspect of the care at home.*' The final question read '*If there is anything else you would like to tell us about any aspect of the care received, or care you would have liked to receive please use the blank space below.*'

Data analysis

Quantitative analysis

We performed all statistical analysis in Stata SE version 14 (Statistical Software: Release 14. College Station, TX: StataCorp LP). We imputed missing data where respondents indicated that a service was used but not how many times, using median number of contacts. All other variables were analysed as completed cases where missing data was <15%.

Explanatory variables with high or moderate strength of evidence of an association with end of life ED attendances from a systematic review [10], or with a bivariate association with the primary outcome at $P < 0.2$ were considered for inclusion in the multivariable regression model. We used multivariable modified Poisson regression analysis with robust error variance [22] to estimate the adjusted prevalence ratio for multiple ED attendance in the last three months of life. We forced age, gender and study in the model as these variables were identified as potential confounders. We employed manual backward selection, informed by the Wald statistic, to determine the variables that would remain in the final parsimonious model.

We explored the impact of missing data on the findings using sensitivity analyses. We conducted subgroup analysis to investigate the impact of including decedents who spent ≥90% (81 days) of the last three months in hospital.

Analysis of free-text responses

We employed a directed content analysis approach, which uses existing literature and theory to inform data coding [23]. We used the findings from the quantitative analysis and theoretical understandings on health services utilisation towards the end of life [17, 18] to inform the initial coding. We were attentive to divergent or emergent concepts evident in the text.

Data integration

We integrated quantitative and free-text findings using a visual conceptual model of factors associated with ED attendance towards the end of life, based on an adapted model of place of care at the end of life [17].

Results

The pooled dataset included 688 responses (IARE study n = 245; OPTCare Elderly n = 443), with responses from 42.0%. Mean age at death was 84.7 years (range 65–104) (Table 1). Most decedents were female (n = 395, 57.4%) and White (n = 631, 95.3%). 262 (38.6%) lived alone and 230 (33.4%) spent time in a care home. 251 decedents had primary diagnosis of cancer (36.5%), 180 circulatory disease (26.2%) and 112 respiratory disease (16.3%). Most respondents were sons/daughters (n = 416, 61.1%) or the spouse/partner of the deceased (n = 150, 22.0%). Respondents' mean age was 62.1 years (range 30–92 years); 66.8% were female.

Patterns of ED attendance in the last three months of life

661 (96.1%) respondents provided information about the ED attendance of the decedent. 55.5% had ≥1 ED attendances in the last three months of life (range 0–10) (Appendix 2, available in *Age and Ageing* online.). Eighty (12.1%) attended the ED ≥ 3 times in the last three months of life, accounting for 43% of all participants' end of life ED attendances.

Factors associated with frequent end of life ED attendance

Table 2 reports the findings from the multivariable analysis. In an adjusted model, those with respiratory disease were more likely to have frequent ED attendances compared to those with cancer (adjusted prevalence ratio (aPR) 2.12, 95% CI 1.21–3.71). Older adults with two or more comorbidities were also more likely to have frequent ED attendances compared to those with zero comorbidities (aPR 1.81, 95% CI 1.07–3.06). We found a strong positive association between community nursing contacts and frequent ED attendance, with a dose response (1–6 contacts aPR 1.90, 95% CI 1.14–3.17; ≥7 contacts aPR 2.65 95% CI 1.49–4.72, reference group zero contacts). Those who identified having a 'key health professional he/she could rely on to get things done' had reduced risk of frequent end of life ED attendances (aPR 0.58, 95% CI 0.37–0.88). We found no association with spending time in a care home (aPR 0.97, 95% CI 0.54–1.76), or discussing preferences about place of care at end of life (aPR 1.19, 95% CI 0.75–1.90).

Sensitivity analyses exploring the effect of imputed values demonstrated consistent findings as did subgroup analysis of those who spent ≥90% of the last three months in hospital (Appendix 3, available in *Age and Ageing* online.).

Family members' own words

From the 80 bereaved family members whose relative had frequent end of life ED attendances, 47 (59%) provided free-text comments. We identified four key themes influencing older adults' frequent end of life ED attendance (Appendix 4, available in *Age and Ageing* online.):

- **Community services' responsiveness to changing needs**, encompassing family members' role as patient advocate to access services, and ED as a cry for help: ID10155 '*At the second ambulance visit, I made him go to hospital, even though he did not want to. That is finally when I got help*'.
- **Involvement of multiple health professionals** with poor coordination leading to confusion and mistakes, ID200028 '*too many people spending too little time…meant that things got missed/forgotten – such as Mum's medication!!*'
- **Untimely and unprepared discharge from hospital** resulting in readmission. ID800573 '*I was given very little notice about his discharge. A Doctor told him he could be discharged when he was clearly not well enough to go home.*'

Table 1. Characteristics of decedents by study setting

Characteristic	South Coast (*N* = 443)		London (*N* = 245)		Overall (*N* = 688)	
	n	Column %	*n*	Column %	*n*	Column %
Age in years						
Mean (SD)	87.4	(6.4)	79.7	(8.3)	84.7	(8.0)
Median (Range)	88	(75–104)	79	(65–101)	85	(65–104)
Gender						
Male	181	40.9	112	45.7	293	42.6
Female	262	59.1	133	54.3	395	57.4
Ethnicity						
White	425	99.3	206	84.1	631	95.3
Black African/Caribbean	0	0	18	7.4	18	2.7
Asian	0	0	5	2.0	5	0.8
Other	3	0.7	5	2.0	8	1.2
Income						
Living comfortably	210	49.8	117	48.6	327	49.3
Doing alright	141	33.4	95	39.4	236	35.6
Just getting by, or finding it quite/very difficult	71	16.8	29	12.0	100	15.1
Primary diagnosis						
Cancer	105	23.1	146	59.6	251	36.5
Ischaemic heart disease	69	15.6	7	2.9	76	11.1
Cerebrovascular	23	5.2	10	4.1	33	4.8
Other circulatory	52	11.7	19	7.8	71	10.3
Respiratory	90	20.3	22	9.0	112	16.3
Dementia	67	15.1	15	6.1	82	11.9
Frailty	21	4.7	2	0.8	23	3.3
Other	16	3.6	24	9.8	40	5.8
Comorbidities Count (Charlson conditions)						
0	265	59.8	100	40.8	365	53.1
1	142	32.1	85	34.7	227	33.0
2	29	6.6	41	16.7	70	10.2
≥3	7	1.6	19	7.8	26	3.8
Marital status						
Married	115	29.1	114	48.5	229	36.4
Not married (single/divorced/widowed)	280	70.9	121	51.5	401	63.7
Living status						
Lived alone	185	42.2	77	32.0	262	38.6
Lived with others	253	57.8	164	68.1	417	61.4
Spent time in a care home						
Yes	200	45.2	30	12.2	230	33.4
No	243	54.9	215	87.8	458	66.6
General Practitioner visits						
0–1	73	19.6	59	25.1	132	21.7
2–3	119	31.9	111	47.2	230	37.8
≥4	181	48.5	65	27.7	246	40.5
Community nurse visits						
0	181	41.9	118	48.6	299	44.3
1–6	180	41.7	85	35.0	265	39.3
≥7	71	16.4	40	16.5	111	16.4
Key health professional to rely on						
Yes	214	53.0	131	58.5	345	54.9
No/don't know	190	47.0	93	41.5	283	45.1
Discussed end of life preferences						
Yes	101	23.2	78	33.1	179	26.7
No/don't know	334	76.8	158	67.0	492	73.3
Place of death						
Own home	112	25.3	51	20.9	163	23.7
Home of friend/relative	8	1.8	5	2.1	13	1.9
Hospice	23	5.2	21	8.6	44	6.4
Hospital	162	36.6	151	61.9	313	45.6
Care home	138	31.5	16	6.6	154	22.4
Area						
City	220	49.7	245	100	465	67.6
Rural/urban	223	50.3	0	0	223	32.4

Table 2. Multivariable analysis using modified Poisson regression to examine the association between sociodemographic, illness and service factors and the outcome ≥3 ED attendances in the last 3 months of life

	Unadjusted estimates		Adjusted estimates*	
Explanatory variables	Prevalence ratio	95% CI	Prevalence ratio	95% CI
Sociodemographic variables				
Gender				
Male (ref)				
Female	0.85	0.56–1.28	1.02	0.66–1.59
Age				
Age in years (continuous, all >65 years)	**0.97**	**0.94–0.99**	0.97	0.95–1.01
Illness variables				
Diagnosis				
Cancer (ref)				
Circulatory	0.62	0.35–1.10	1.09	0.56–2.09
Respiratory	1.25	0.75–2.09	**2.12**	**1.21–3.71**
Other	0.61	0.33–1.15	1.22	0.61–2.45
Number of Charlson co-morbidity conditions				
0 (ref)				
1	1.22	0.74–2.02	1.14	0.68–1.91
≥2	**2.84**	**1.76–4.58**	**1.81**	**1.07–3.06**
Service variables				
Spent time in care home				
No (ref)				
Yes	0.62	0.38–1.01	0.97	0.54–1.76
Community nurse visits				
0 visits (ref)				
1–6 visits	**1.79**	**1.09–2.95**	**1.90**	**1.14–3.17**
≥7 visits	**2.45**	**1.42–4.25**	**2.65**	**1.49–4.72**
Key health professional to rely on?				
No/Don't know (ref)				
Yes	**0.65**	**0.42–1.00**	**0.58**	**0.37–0.88**
Preferences discussed with health professional				
No/ Don't know (ref)				
Yes	1.46	0.96–2.25	1.19	0.75–1.90

PR = prevalence ratio; CI = confidence interval; ref = reference or baseline group; bold font represents significant association where alpha <0.05 *model adjusted for all variables in the model and adjusted for study.

- **Feeling unsafe and lacking confidence in care and support** in the community as a reason for seeking care from the hospital, ID10037 *'The family did not feel well supported by the medical/palliative teams whilst patient was ill at home. Medication regime was complex and patient lost confidence in administering drugs at correct time.*'

Discussion

In this study of 661 decedents aged ≥65 years, 12.1% had ≥3 ED attendances in the last three months of life, accounting for 43% of all such attendances. Illness or need factors were important influences of ED attendance (Figure 1). Those with a primary diagnosis of respiratory disease, and with multiple comorbidities were more likely to have frequent end of life ED attendances. Key opportunities are to improve the management of care for individuals living with multiple conditions and unstable symptoms, notably breathlessness. There are examples of interventions to support complex and refractory symptoms for those towards the end of life [24]. Understanding how these can be applied to the older population living at home or in care homes is an important and emerging area for policy, given that over two-thirds of all deaths could occur in these settings by 2040 [5].

Service or enabling factors are important to understand as they are most amenable to change [18]. Continuity of care across settings and multiple providers of care for those with multiple conditions, is important to prevent unnecessary repeat attendances. We found that greater contacts with community nursing was associated with higher likelihood of frequent ED attendances. The free-text comments were illuminating, revealing that having many health professionals caused confusion with detrimental effects on care quality. This suggests that increasing the number of short, task-focused visits by community health professionals will not necessarily provide the support required for the person to remain at home. Instead, our findings suggest that older people approaching the end of life would be supported by a key health professional who assesses, coordinates and provides holistic care within a multidisciplinary team [25]. More

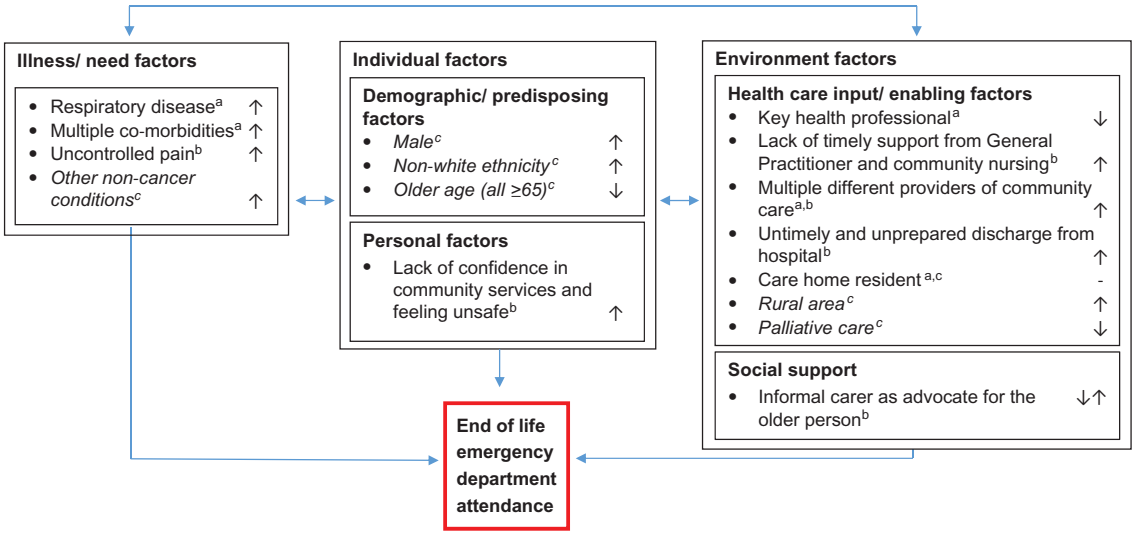

Figure 1. Explanatory model for older people's ED attendance towards the end of life. a. Factors associated with frequent end of life ED attendance from quantitative findings; b. Factors identified as influences of frequent end of life ED attendance from the free-text responses; c. Factors associated with ED attendance in the last year of life (high or moderate strength evidence) from recent systematic review [10]. ↑ Evidence that factor increases ED attendance; ↓ Evidence that factor decreases ED attendance; - no evidence of effect.

broadly, research exploring the effectiveness of key workers has been mixed [26, 27], although interpreting such findings is challenging due to study heterogeneity and varying terminology (e.g. case manager; care coordinator). Whilst we present new and encouraging data to support the value of key worker involvement in the care of this population, specific models of care incorporating a key worker for older people towards the end of life require further testing.

Untimely discharge from hospital and inadequate consultation with family members precipitated readmission via the ED. Overburdened hospitals face pressure to discharge patients early, and possibly without adequate support in the community to prevent readmission. Consistent with previous studies of cancer patients [28], the free-text responses also showed that ED attendance may be influenced by family member's confidence in the competence of health professionals and feeling safe. Services need to prioritise vulnerable patient groups such as older people with multiple comorbidities, and socially isolated without a person to advocate for them.

This study builds evidence on factors that influence frequent end of life ED attendance. Inclusion of family members reporting on an older person's last months of life, is little considered in the literature [11]. Integrating findings from open and closed survey responses allowed for a richer understanding of frequent ED attendances towards the end of life. Responses from 42%, while typical for postal bereavement surveys, introduces a potential response bias. Given the deaths occurred four to ten months prior to survey completion, there is also potential for recall bias. However, agreement between proxies and patients at the end of life has shown to be reasonable for objective measures, such as service use [29]. From these data, we were unable to determine whether ED attendances were appropriate or avoidable. The cross-sectional study design means that cause and effect cannot be determined; a prospective examination of these associations is required. As this was a secondary analysis, we were limited by the data previously collected. The OPTCare Elderly study had a greater number of responses, and in our pooled sample cancer was slightly overrepresented and dementia underrepresented compared to national figures [30], thereby limiting generalisability. For the free-text analysis, our purposive sampling approach meant we only considered the experiences of those who had frequent end of life ED visits.

Conclusion

A model of care involving a key health professional responsible for communicating with the older person and family and co-ordinating care may reduce ED attendance towards the end of life, particularly for those with multi-morbidity and/or respiratory disease. There is an imperative to evaluate service models of care for older people with multi-morbidity and non-cancer conditions living in the community to improve care towards the end of life for older people.

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Acknowledgements: We thank the participants for sharing their stories about their loved ones. We thank BuildCARE (IARE I) and the OPTCare Elderly research teams and all collaborators and advisors.

BuildCARE (Building Capacity, Access, Rights and Empowerment) is an international research programme that aims to create a 'sea change' in the way palliative and

end of life care is regarded, implemented and prioritised internationally. The following are members of the BuildCARE team: Emma Bennett; Francesca Cooper; Barbara Daveson; Susanne de Wolf-Linder; Mendwas Dzingina; Clare Ellis-Smith; Catherine Evans; Taja Ferguson; Lesley Henson, Irene J Higginson; Bridget Johnston; Paramjote Kaler; Pauline Kane; Lara Klass; Peter Lawlor; Paul McCrone; Regina McQuillan; Diane Meier; Susan Molony; R Sean Morrison; Fliss Murtagh; Charles Normand; Caty Pannell; Steve Pantilat; Anastasia Reison; Karen Ryan; Lucy Selman; Melinda Smith; Katy Tobin; Rowena Vohora; Gao Wei; Deokhee Yi.

OPTCare Elderly aims to develop and evaluate the feasibility of a short-term integrated palliative and supportive care service for frail elderly people with non-malignant conditions living at home or in a care home. OPTCare Elderly is a joint project between King's College London and Sussex Community NHS Foundation Trust. The following are members of the OPTCare Elderly Team: Catherine J. Evans; Irene J Higginson; Myfanwy Morgan; Paul McCrone; Wei Gao; Juliet Wright; Sue Hall; Barbara Gomes; Emma Gordon; Fiona Lindsay; Carla Bruni; Shamim Taherzadeh; Richard Harding; Katherine E. Sleeman; Matthew Maddocks; Helen Harris; Anita Wright; Sue Guerrier; John Barry; Lesley Talmey; Colin Vincent; Mike Bojczuk; Jack Hazelgrove; Anna E. Bone; Deokhee Yi; Rowena Vohora; Katie Stone; Mark Philips; Nina Walters; Kate Porter; Claire Cox.

Declaration of Conflict of Interest None.

Declaration of Sources of Funding This work is independent research funded by Cicely Saunders International and The Atlantic Philanthropies (grant number 24610). The IARE I study was independent research supported by Cicely Saunders International and the Atlantic Philanthropies (Grant number 191219). The OPTCare Elderly Study was funded by the National Institute for Health Research (NIHR) Research for Patient Benefit Programme (Project PB-PG-1111–26071). The sponsor had no role in the design, methods, subject recruitment, data collection, analysis or preparation of this paper.

This research was supported by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London, which is part of the National Institute for Health Research (NIHR), and is a partnership between King's Health Partners, St. George's, University London, and St George's Healthcare NHS Trust. CJE holds a HEE/NIHR Senior Clinical Lectureship and IJH is an Emeritus NIHR Senior Investigator. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

References

1. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013; 12: 7.
2. Sleeman KE, Perera G, Stewart R, Higginson IJ. Predictors of emergency department attendance by people with dementia in their last year of life: retrospective cohort study using linked clinical and administrative data. Alzheimers Dement 2018; 14: 20–7.
3. Abraham S, Menec V. Transitions between care settings at the end of life among older homecare recipients: a population-based study. Gerontol Geriatr Med 2016; 2: 2333721416684400.
4. Gruneir A, Silver MJ, Rochon PA. Emergency department use by older adults: a literature review on trends, appropriateness, and consequences of unmet health care needs. Med Care Res Rev 2011; 68: 131–55.
5. Bone AE, Gomes B, Etkind SN *et al*. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliat Med 2018; 32: 329–36.
6. Marie Curie. Emergency admissions: Data briefing. 2018.
7. Bone AE, Evans CJ, Higginson IJ. The future of end of life care. Lancet 2018; 392: 915–6.
8. Prince MJ, Wu F, Guo Y *et al*. The burden of disease in older people and implications for health policy and practice. Lancet 2015; 385: 549–62.
9. Steptoe A, Shankar A, Demakakos P, Wardle J. Social isolation, loneliness, and all-cause mortality in older men and women. Proc Natl Acad Sci USA 2013; 110: 5797–801.
10. Bone AE, Evans CJ, Etkind SN *et al*. Factors associated with older people's emergency department attendance towards the end of life: a systematic review. Eur J Public Health 2019; 29: 67–74. doi:10.1093/eurpub/cky241.
11. Thwaites R, Glasby J, Le Mesurier N, Littlechild R. Interviewing older people about their experiences of emergency hospital admission: methodology in health services research. J Health Serv Res Policy 2019; 24: 124–129.
12. UK Clinical Research Network. The IARE study. In: Portfolio database. London: UK Clinical Research Network, 2014.
13. Bone AE, Gao W, Gomes B *et al*. Factors associated with transition from community settings to hospital as place of death for adults aged 75 and older: a population-based mortality follow-back survey. J Am Geriatr Soc 2016; 64: 2210–7.
14. Gomes B, McCrone P, Hall S, Koffman J, Higginson IJ. Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. BMC Cancer 2010; 10: 400.
15. McCrone P. Capturing the costs of end-of-life care: comparisons of multiple sclerosis, Parkinson's disease, and dementia. J Pain Symptom Manage 2009; 38: 62–7.
16. EuroQol EQ5D. 2018; Available from: https://euroqol.org/eq-5d-instruments/ [last accessed 18/04/2019].
17. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ 2006; 332: 515–21.
18. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995; 36: 1–10.
19. Ambitions for Palliative and End of Life Care. Metrics for End of Life Care – Paper L. 2017 [27/11/2017]; Available from: http://endoflifecareambitions.org.uk/programme-board-papers/ [last accessed 18/04/2019].
20. Henson LA, Gao W, Higginson IJ *et al*. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. J Clin Oncol 2015; 33: 370–6.
21. Sundararajan V, Henderson T, Perry C, Muggivan A, Quan H, Ghali WA. New ICD-10 version of the Charlson comorbidity

index predicted in-hospital mortality. J Clin Epidemiol 2004; 57: 1288–94.
22. Zou G. A modified poisson regression approach to prospective studies with binary data. Am J Epidemiol 2004; 159: 702–6.
23. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005; 15: 1277–88.
24. Higginson IJ, Bausewein C, Reilly CC *et al*. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med 2014; 2: 978–87.
25. Evans CE, Ison L, Ellis-Smith C *et al*. Service delivery models to maximise quality of life for older people at the end-of-life: a rapid review. Milbank Quarterly 2019; 97: 113–75.
26. Huntley AL, Johnson R, King A, Morris RW, Purdy S. Does case management for patients with heart failure based in the community reduce unplanned hospital admissions? A systematic review and meta-analysis. BMJ Open 2016; 6: e010933.
27. Addington-Hall JM, MacDonald LD, Anderson HR *et al*. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. BMJ 1992; 305: 1317–22.
28. Henson LA, Higginson IJ, Daveson BA *et al*. 'I'll be in a safe place': a qualitative study of the decisions taken by people with advanced cancer to seek emergency department care. BMJ Open 2016; 6: e012134.
29. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med 2003; 56: 95–109.
30. Office for National Statistics. Deaths Registered in England and Wales (Series DR). 2015; Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables [last accessed 18/04/2019].

Received 7 December 2018; editorial decision 29 March 2019